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ABSTRACT

The quality of life for individuals with disabilities depends on access to quality services and employment opportunities. It is also important that the disabled be accepted as participating, contributing, and cherished members of the community. Distance and isolation, which typify rural areas, directly impact each of these issues. Individuals with disabilities have significant contributions to make to rural communities, and education of the rural disabled has a twofold purpose: (1) to increase their skills and knowledge as individuals; and (2) to educate communities about their potential. The Education for All Handicapped Children Act (Public Law 94-142) established that public education has a responsibility to provide education for all children and required substantial and system-wide changes in providing such education. These changes have had a disproportionate impact on the budgets of rural schools and have created problems. Small, rural schools need waivers from categorical funding requirements so that all children experiencing problems in school can benefit from the skills, technologies, and processes developed by special education. Pull-out programs need to be replaced by specialized support and consultative help from itinerant specialists for classroom teachers. Small schools have few self-contained classrooms and need permission to experiment with model programs. Computers and augmentative communication boards need to be provided by PL 94-142 to rural schools. These waivers and special provisions to PL 94-142 would enable rural schools to educate the disabled to be productive in the rural community. (ALL)

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THE RURAL EDUCATION AGENDA:

EDUCATION FOR INDIVIDUALS WITH DISABILITIES

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THE RURAL EDUCATION AGENDA

EDUCATION FOR INDIVIDUALS WITH DISABILITIES

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This speech is based on a paper co-authored by Eula Boelke, Family Advocate in Grand Junction, Colorado and Toni Haas, Co-Director of the Rural Institute, Mid-continent Regional Education Laboratory (McREL).

Who are the rural disabled? The rural disabled are children and adults. They are babies born with disabilities, children struck by disease, adult victims of farming, mining or other accidents while working, adult and children who are in automobile crashes, who are saved from drowning. Many are people who have simply grown old and frail. There is evidence that we are all "temporarily able-bodied", that if we live long enough, we all become disabled.

The risk for becoming disabled in rural America is higher than in other parts of the country, for several reasons. Rural health care is stretched thin by vast distances. There are fewer available services for people who need just a little help, so the options become polarized into total independence or total dependence. The economic base of rural areas (agriculture, mining and other extractive industries) represent the most dangerous of occupations. In 1983, according to the National Safety Council statistics, agriculture replaced mining as the most hazardous occupation in America, and logging is number three.

How does rurality impact on quality of life for people with disabilities? The population of people with disabilities is the same in rural America as in all America, only more so. The same thing is true of the issues. The quality of lives for individuals with disabilities depends on access to quality medical, education and social services, access to employment opportunities, access to adequate housing, access to transportation and to acceptance as a participating, contributing and cherished member of the community.

Distance and isolation, which typify rural areas, directly impact each of these issues. Our task today is to focus on education. However, briefly let me suggest to you how being rural and disabled represents double jeopardy.

Access to quality medical care is the first issue. Medical care in America is a combination of private enterprise and programs supported by the federal government, specifically Medicare, Medicaid and Social Security. This means that health care workers who mean to maximize the return on their training investment will set up practices in areas where dense populations provide strong markets for their services. Certain specialists chose to practice in population centers (it is difficult, for instance, to find neonatal experts practicing in county seats of orthopedic surgeons in small towns.)

There are strong anti-rural biases in the federal medical programs as well. Reimbursement formulas assume unrealistically lower costs of providing health care in rural areas, when the opposite is often the case. The epidemic of rural hospital and care facility closings (more than 40 this year, more than 206 since 1980) is evidence of these false economies. Each time a rural hospital closes, emergency medical services move farther away, it takes longer for ambulances to reach the scene, longer to transport back to facilities, and risk for death or permanent disability after accidents increases.

Access to social services is the second issue. Rural America has not participated in the economic growth experienced by both coasts and urban areas in the past five years. That results in a drain of taxpayers as residents leave for employment opportunities elsewhere. Shrinking land values (in the Midwest estimated to have fallen by 50 percent since 1980) also bleed the tax roles. States and counties are forced to cut back on already stretched social service budgets. For rural Americans, this means, among other things, fewer home health aides and respite services, more stress on families and people with disabilities who can no longer live independently.

Access to employment is the third issue. Employment services have likewise been cut, and individuals with disabilities may suffer most in periods of economic decline like the one rural America is experiencing. We will touch on employment issues again when we talk about education.

Access to adequate housing is the fourth issue. Rural America is the sector where housing stock is in the greatest disrepair. It tends to be older than urban housing stock, there has been more reliance on prefabricated housing and mobile homes that depreciate quickly and are difficult and expensive to repair, and loan programs such as the Farm Home Administration have never been fully funded. Old rural housing stock tends not to be accessible, with steep stairs, narrow hallways and tiny bathrooms. This, again, limits mobility, choices and independence for individuals with disabilities.

Access to transportation is the fifth issue. Mobility is limited in another way because transportation systems are scarce and accommodations to mobility impairment hard to find. Not only are there few public systems equipped with chair lifts, there are few curb cuts (or sidewalks for that matter) and moving even a motorized chair down an unpaved road presents real challenges.

Access to participation in the community is the final issue. Lack of access to transportation can restrict participation in community events, obviously. One of the strengths of rural communities is that each individual counts. Because there are few people, each is important. Rural individuals with disabilities have significant contributions to make to rural communities and we need to find ways to take advantage of their presence.

Education is one such way, and has a twofold purpose: to increase their skills and knowledge as individuals and to educate communities about their potential. For most of the history of public education in America, young people with disabilities were simply invisible. Either their disabilities went undiagnosed and they were thought to be stupid, unmotivated or unruly or they were not present at all, locked up at home or shipped off to institutions. Twenty years ago, Public Law 94-142 all that. It created public policy that says public education has a responsibility to all America's students.

This law has had far reaching effects on all education and on how we as a society view persons with disabilities. PL 94-142 has three revolutionary conditions. It requires that all children, regardless of their mental or physical condition be offered meaningful educational opportunities commensurate with their level of development or need, that children be educated with their peers in the least restrictive environments, and insists, in very specific ways, that parents be included in planning meaningful learning activities.

Parents accepted the challenge to learn, along with educators, to serve children with disabilities, with alacrity. They proved eager to be an active part of the educational process. Adult populations are better educated themselves, and confident that they can make a contribution to the system. The integration of children with disabilities has increased societies understanding of the many more ways these children are like others than they are different. We have all learned from on another. Initial resistance, based on fear and ignorance, has yielded to better understanding of how we all benefit from one another.

Providing quality education in rural America is the task. PL 94-142 required substantial and system-wide changes in the way we think about and provide education. These changes have had a disproportionate impact on rural schools. The law has never been fully funded from the federal level, and small schools with small budgets are subject to the same regulations as all schools. Meeting the regulators in the law sometimes gets in the way of providing services. While these regulations initially may have been necessary to protect fundamental rights and develop new understandings, as educators and parents we are now convinced. It is time to create new ways to provide services that fit local, particularly rural contexts.

Categorical funding presents one problem. Special education has developed technologies, processes and skills important for quality education of all children. Funding is now tied to specifically defined disabilities. Small, rural schools need waivers from categorical funding requirements so that all children experiencing problems in school can benefit. Interactive teaching and learning could take place in small, manageable classroom settings. All student learning would increase and the cost ratio per student would decrease, dramatically.

Itinerant and consultative services is a second area. Research shows that pull-out programs (which include Chapter One reading as well as special education services) often have the opposite of intended effects. Regular classroom teachers need specialized support and consultative help from itinerant specialists operating from regional centers for their entire classes. This organizational approach, bringing the services to the students rather than the students to the services, has proven successful in many parts of the country. It should be expanded to embrace all rural students and classes, and be a legitimate option under the law.

Small settings and more integration provide greater student benefits, and rural schools can model this for the rest of the country. Budget constraints and low incidence of students often have resulted in few rural self contained classrooms. Necessity helped invent procedures where special services are provided more, not less effectively in the regular classrooms with proper materials and support. Permission to experiment with model programs to provide materials and supports can be bolstered by better ways to measure student progress and outcomes, demonstrating accountability while operating outside the current regulations.

Technology has an important role to play. The explosion of technology such as computers and augmentative communication boards that improve the quality of life for students with disabilities means equipment is available to rural schools, but at a proportionately greater cost because there are fewer students with special needs. Outside support is necessary, and PL 94-142 should make provisions to bring equipment to rural areas in the same way NSF makes investments in upgrading University laboratory equipment in the national interest.

Employment services appropriate for rural economics can be developed. There are exciting models for employing rural youth with disabilities, ranging from entrepreneurship training that creates new businesses through the guided employment training provided for organizations such as the Black Hills Special Services Cooperative in South Dakota. Employability and transition to work programs are an important component of rural school's curriculum for all students. Again, special education has a contribution to make for general education.

Community Development: Who belongs here? Hubert Humphrey used to say that the test of a moral society is how it cares for its most vulnerable members. Work remains to be done in the areas attitudes and how we include and care for one another. In rural areas, new kinds of students can present challenges that teachers feel unequipped to meet. Expectations can be lowered, based on notions that "that family is not adequate, or bright, or worthy, they've always been like that." We need to put significant resources and energy into making sure teachers, families and students feel supported as they cope with the challenges of disabilities. Familiarity and experience with persons with disabilities help, especially when enhanced with carefully designed inservice based on research, fact and celebrations of carefully documented success.

Respite Care is essential. One service missing in many rural areas is respite care. Intact, fully functioning families provide the best environment for all of us to grow. We have a stake in supporting families, helping them answer questions such as "How do I get relief from the burdens of constant care?" "How can the rest of the family get their needs met?" Federal funding for a national respite care program is a critical factor for helping children stay in their homes and communities where they can make their contribution to the common good. Such funding should be considered catastrophic family health insurance, and has cost benefits that far exceed the costs of institutionalization, which is often the only other option.

Community Guides are a new notion particularly suited to rural areas. Some fortunate small towns are blest with what John McKnight calls "community guides". These are individuals who have strong ties throughout the community, know what services are available and "ferry" people who have needs to people who can help. They create informal networks and match needs to solutions outside the regular channels. A way to identify these "guides", learn from them and teach others to provide this function is necessary, and demonstrations of this work need immediate funding. "Community guides" provide a dynamic example of capitalizing on rural traditions of self sufficiency, of helping people to help themselves, and of neighbors helping neighbors.

To sum up: Community guides could interface with the existing service systems, pushing them to address barriers to quality lives for rural individuals with disabilities. They could address problems of access to quality medical care by arranging for the local medical personnel to attend seminars on dealing with patients with disabilities (dentists may need special techniques to work with students with cerebral palsy, for example). They could help modify recreation and other social programs so they become more accessible to people with disabilities. They could work on increasing access to employment, provide information on building accessible new housing and modifying existing buildings, and develop alternative forms of transportation. Most of all, they could guide the community to understand the benefits of increased participation of all residents.

Stephen Hawking, the brilliant author, has translated his conception of the origins of the universe for laypeople in *A Brief History of Time*. Hawking, who can neither move nor speak independently, is only one example of the spiritual and intellectual resource represented by individuals with disabilities. How many more live in rural America, and how important is it to each of us to do our part to make sure we have the benefit of each and every one of them.?